

Children with Epilepsy

A Study of Their Needs in California

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AN ACT³ OF THE 1959 California Legislature directed the State Department of Public Health to conduct a three-year research study of the needs of California children with epilepsy and to determine the need, costs and feasibility of broadening the Crippled Children Services program of diagnostic, consultative and treatment services to include children handicapped by epilepsy. Testimony⁵ pointing up the need for such services had been presented to the Legislature in 1957 and 1958 by physicians, representatives of health departments and leaders of voluntary agencies interested in handicaps of children. Because neither the number of children needing such services nor the quantity of services could be accurately estimated for the entire state, it was decided to establish a pilot demonstration program in two geographical areas in order to anticipate the needs and costs for such services on a statewide basis.

The Epilepsy Study Project team was assembled in 1960 to implement this legislation, and the following major objectives were established:

1. To determine the number and kind of children with epilepsy who need diagnostic and treatment services under Crippled Children Services.
2. To determine the kinds of services needed, and the costs, problems, and results of providing such services.
3. To determine the level of social functioning of these children and their families.

In order to gather the data and information required by the legislation and these objectives, demonstration programs of diagnostic and treatment services were established in Contra Costa County in the north and in San Bernardino County in the south. These counties had a population of such size that the expected case loads could be diagnosed and treated within the amount of the appropriation. Each of them had a health department which was aware of the problems of epilepsy and

• The 1959 California Legislature directed the State Department of Public Health to conduct a study of the needs of California children with epilepsy and to determine the costs and feasibility of including medical services to such children under the Crippled Children Services program. A demonstration program of services was provided in Contra Costa and San Bernardino counties. Under these programs, children suspected of having epilepsy were referred for specialists' examinations, tests and recommendations for treatment.

Private physicians provided the largest portion of a total of 236 referrals. Children referred were found to have complex medical, social and educational problems, and to be in need of comprehensive diagnostic and treatment services.

About half of the children had mixed epilepsy and over one-third had focal seizures. Two-thirds had at least one other major additional handicap. At the time of referral one-fifth of these children had one or more seizures daily.

Through specialized care and medications provided under this project, 58 per cent of those with seizures became seizure free, and an additional 24 per cent showed a considerable reduction of seizure frequency.

This project provided a practical method of obtaining information necessary for program planning and has also demonstrated the value of such a program in helping private physicians to meet some of the multiple problems presented by these children.

was willing to cooperate with the State Health Department in providing this care on a pilot basis.

PROVISION OF SERVICES

The services which were provided in Contra Costa and San Bernardino counties were developed after study of programs in other states and after consultation with epilepsy specialists in medical centers in California. The program of services began in Contra Costa County in October, 1960, and in San Bernardino County in May, 1961, although referrals were accepted before these dates. The policy of diagnostic, consultative, and treatment services has been similar to that of other operating programs under Crippled Children Services.

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DIAGNOSTIC SERVICES PROVIDED

1. Diagnostic pediatric examination.
2. Neurological consultation.
3. Examination by other specialists as indicated.
4. Laboratory studies (including electroencephalogram).
5. Psychological evaluation of pre-school children and school age children when not available from the schools.
6. An assessment of the social functioning of the family and the child.
7. Case conference.
8. Interpretation conference with parents and child.

All children received special diagnostic examinations by designated pediatrician specialists interested in epilepsy. In Contra Costa County, a neurologist also examined all children and provided consultation to the pediatrician on all cases during the first year of operation. Later, the neurologist provided consultation only on referral by the pediatrician for difficult or problem situations. In San Bernardino County, the pediatric specialist had had extensive training and experience in the field of childhood epilepsy, and a neurologist's consultation was rarely utilized. It was necessary for some children in both areas to have consultative examinations by other specialists such as psychiatrists, ophthalmologists and neurosurgeons.

Routine diagnostic laboratory studies were obtained from local laboratories and hospitals, and included a complete blood count, serological test for syphilis, urinalysis (including the phenylketonuria test), tuberculin skin test and an electroencephalogram. Other appropriate tests that were carried out when indicated included x-ray films of the skull, glucose tolerance tests and spinal fluid examinations.

A few children had received some recent diagnostic tests at the time of referral by their private physicians and these were not repeated. Additional tests were then carried out to complete the examination.

Psychological evaluations were performed by local psychologists with special experience in testing handicapped children. These clinical psychologists utilized a battery of screening tests to determine performance in the areas of intelligence, perceptual-motor functioning, associative learning, problem-solving and academic achievement.

The assessments of social functioning of each family and selected children were performed by the medical social worker of the Epilepsy Project staff, who interviewed the parents by utilizing a specially developed guide² in examining five specific areas

of family functioning: Adult, marital, financial, child-rearing and child functioning.

The case conference, which had been one of the most important features of this program of services, was held after the initial diagnostic studies were completed. Participating in this conference were the pediatrician, neurologist, social worker, public health nurse and in most instances the psychologist. The child's private physician was invited to attend and participate and was reimbursed for his service. The child's teacher, school principal, counselor and/or school nurse, and when appropriate, representatives of social agencies (welfare and probation departments, vocational rehabilitation services) were also invited to this conference. The reports of the specialists of the various disciplines who had examined the child and his family were reviewed and discussed by members of the conference, and if possible, a final diagnosis was made. The planning of treatment and coordination of services to meet identified needs was carried out and the responsibility for follow-up was assigned. During these conferences, inter-professional communication and education took place, making available to referring physicians the Project's diagnostic findings of their patients and current principles of diagnosis and treatment of persons with epilepsy. The increased understanding of the child's condition by his teacher was important to the child's education. It was also important for the teacher to be able to teach a modern understanding of epilepsy to the child's classmates, particularly if seizure symptoms should occur during classtime.

After the case conference, both the mother and the father were urged to attend an interpretation conference with the examining physician.¹ Time was provided to discuss and interpret the findings, conclusions and recommendations of the case conference, to answer the many questions that often arise as to the medical and social implications of the diagnosis of epilepsy, and to emphasize the need for continuous medical supervision and anti-convulsant drug therapy for many years. This visit with the parents and the child himself was found to be an important adjunct to the other services provided; it implemented the cooperation and understanding of the family of the child's medical and social needs.

The families of children who did not have epilepsy were also provided with an interpretation conference and were assisted in finding the appropriate resources for their child.

According to Crippled Children Services' procedure, a financial eligibility determination took place at this point to determine the family's need for assistance. Treatment services which included medical supervision, anti-convulsant drugs, appropriate periodic complete blood cell counts and uri-

TABLE 1.—Sources of Referral of Patients Receiving Diagnostic Services under Epilepsy Study Project

	Contra Costa County (180 Patients)	San Bernardino County (56 Patients)
	Per Cent	
Private physician	43	29
Public health nurse	22	29
School	14	18
Health department clinic	6	9
County hospital	4
Other*	11	15

*Includes other official agencies, voluntary agencies, friends, self, etc.

nary albumin testing, were provided these children by the program if the financial eligibility criteria were met. Some families made partial payment reimbursement plans. Children who had been referred for consultation only, or who were found not to be in financial need, were returned to their referring private physician. Those whose families were in financial need were assigned to the epilepsy specialist for follow-up care. When their medication and seizure control were stabilized, they were returned to their private physician, and the cost of such care was provided by the program.

FINDINGS

Diagnostic services were provided to 236 children from 228 families in the two-year period.

On the basis of various prevalence studies,^{7, 8, 14} it was estimated that in Contra Costa County there were 650 to 880 children with epilepsy out of a total population of 409,030, and in San Bernardino County 750 to 1,030 in a total population of 503,591.⁴ During the two years, 180 children received diagnostic services in Contra Costa County, which represented 10 to 16 per cent of the population estimated to have epilepsy each year. In San Bernardino County, 56 children or 2 to 5 per cent received such services.

Parents learned about the Epilepsy Project from many sources, the most frequent being private physicians, public health nurses and the schools (Table 1). In Contra Costa County, the early referrals were primarily from the latter two sources, but after the initial period, physician referrals increased and accounted for a steady flow of patients. In this county physicians were responsible directly for over 40 per cent of the referrals, and they assisted indirectly in bringing a number of others to the program where the family had learned of it from another source.

In San Bernardino County, physicians referred fewer than 30 per cent of the cases, while public health nurses and schools accounted for a slightly higher proportion than in Contra Costa County.

TABLE 2.—Medical Care Status at Time of Referral of Patients Receiving Services under Epilepsy Study Project

	Contra Costa County (180 Patients)	San Bernardino County (56 Patients)
	Per Cent	
Not currently under medical care	8	30
Currently under medical care	92	70
Never treated for epilepsy	36	25
Previously treated for epilepsy but treatment lapsed	8	14
Currently under treatment	49	30

TABLE 3.—Seizure Control Status of Patients at Time of Referral to Epilepsy Study Project

	Contra Costa County (180 Patients)	San Bernardino County (56 Patients)
	Per Cent	
Currently under treatment	49	30
Not under control	42	28
Controlled; referred because of financial need	7	2

Toward the end of the study period, physician referrals as well as referrals from other sources in San Bernardino County had increased as the availability of services became generally known.

At the time of referral to the Epilepsy Project, the public health nurses inquired as to the medical care status of the patient (see Table 2) and listed the name and address of the child's physician, if any, as well as the source and dates of previous treatment for epilepsy.

A child was considered to be "currently under medical care" if his family named a private or clinic physician to whom they would take a child if they felt that he needed medical care. If the family had been to a physician recently the child was considered "currently under medical care," although the family may not have considered that they had a personal physician. In Contra Costa County, 8 per cent of the children were not currently under medical care, and of these, one in four had never been treated for epilepsy. In San Bernardino, however, 30 per cent were not under medical care, and of these, almost half had never been treated for the condition which brought them to the project.

A child was considered as "never treated for epilepsy" if he had never received any care for his epilepsy from any physician.

In Contra Costa County, over 90 per cent of the families reported they had a physician to whom they took the child for medical care, but for over one-third of these children this physician had not treated the child for seizures. In San Bernardino County, 70 per cent of the children were currently under medical care at time of referral, and here too more than one-third of them had never been treated for epilepsy.

**TABLE 4.—Types of Epilepsy in Patients
Receiving Diagnosis under Epilepsy Study Project
(Information available for 169 patients)**

Single Types	Per Cent
Non-Focal and other	
Grand Mal	33
Petit Mal	6
Minor motor and other types	5
Non-Focal total	44
Focal	12
Total	56

Mixed Types	Per Cent
Grand and Petit Mal	15
Focal, combined with other type[s]	25
Other combinations	4
Total	44

Forty-nine per cent of the Contra Costa County children were currently under treatment for epilepsy at the time of referral (Table 3), but in nearly all of these cases control of the seizures had not been achieved. Of the 30 per cent of the San Bernardino County children who were under treatment, only one child was found to have seizures under control at the time of referral.

Almost half of the children diagnosed as having epilepsy under the program have a mixed variety, that is, two or more different types of seizure patterns (Table 4). Epilepsy of this kind is more complicated and more difficult to diagnose correctly and to treat properly than is that with a single type of seizure.

Thirty-seven per cent, or about one out of every three children in this program, have a focal type of seizure pattern, both as a single and as a mixed diagnosis. This kind of epilepsy is found most often in children who have a history of brain injury or other intracranial disease,^{9, 10} which again points up the fact that many of the children served by this program have the secondary or symptomatic type of epilepsy, with more evidence of cerebral involvement, as we will note further. Consequently they have more problems and difficulties. They also may require close follow-up examinations over a long period to determine whether the seizure is an initial symptom of a progressive neurologic disease (neoplastic or degenerative) or if a static lesion such as an atrophic focus.⁶

Two out of three of the children who were diagnosed as having epilepsy had other handicapping conditions (Table 5), which of course add to the difficulty of treating their seizures. The principal associated handicapping condition was mental retardation. The criteria used to designate retardation was an intelligence quotient determination of less

**TABLE 5.—Per Cent of Patients
With Additional Handicapping Conditions
(Information available for 169 patients)**

	Per Cent
None	34
Mental retardation	37
Severe emotional problems	25
Cerebral palsy	17
Minimal cerebral dysfunction	16
Blindness	2
Deafness	2
Other central nervous system, sense organ lesions	10
Other conditions	10

than 70 or the statement by the examining psychologist that the child was retarded.

There were 199 handicapping conditions in addition to epilepsy in those 169 children diagnosed as having epilepsy. Thirty-four per cent had no other conditions. One-third had two or more handicapping conditions.

Severe emotional problems were found in 25 per cent of the children with epilepsy. A child was considered to have a severe emotional problem if it was determined that he was having difficulties in relating to his parents, the school environment or his peers to such an extent that he needed casework services or psychiatric care.

Minimal cerebral dysfunction was diagnosed in 16 per cent of children with epilepsy. The child with minimal cerebral dysfunction is one who as a probable result of brain damage, impairment or selective brain immaturity has one or more of the following symptoms: Hyperactivity, short attention span, impulsivity, low frustration tolerance, poor muscle coordination and decreased perceptual and conceptual abilities.

Many children had a combination of these conditions. Nineteen had mental retardation, cerebral palsy and epilepsy. Twelve had mental retardation, severe emotional problems and epilepsy, and 16 had a combination of minimal cerebral dysfunction, who had cerebral palsy were not being given care mental retardation, and epilepsy. The 29 children for their epilepsy under the Crippled Children Services program before they received it under this pilot program.

Fifteen per cent of the Contra Costa County families and 18 per cent of the San Bernardino County families were receiving public assistance (Table 6). The allowable welfare budget was calculated for each family, using the welfare budget standards of the Department of Social Welfare for the Aid to Needy Children program for each county. The net family income was compared with this amount, and if earnings did not exceed the budget allowance by more than 20 per cent, the family was considered to be living at a minimum level. Twelve per cent of the families in Contra Costa County and 33 per

cent in San Bernardino County had incomes that were considered minimal. Approximately half of the families in San Bernardino County were considered to be at or below minimal level, while over one-fourth of the Contra Costa County families were in this category. About 10 per cent of the families were able to pay for treatment costs, according to the financial eligibility standards of the county Crippled Children Services program.

Social assessments of family functioning were completed for 228 families representing 236 children. Thirty per cent of the families were classified as having "no significant problems." These families had realistic concerns about medical problems, but were able to successfully cope with stress. They sought and used help in positive and constructive ways. Forty-four per cent of the families had "moderate problems." They had impairment in coping with stress and these families chronically functioned below their maximum abilities. Many of them appeared to have continual setbacks, such as periodic illnesses during which time they were unemployed and had to rely upon community agencies for financial support. Twenty-six per cent of the families had long-standing and serious social dysfunctioning and were classified as having "severe problems." These family units were likely to be structurally and emotionally disintegrated and the parents frequently manifested symptoms of severe emotional disturbances.

The study identified need for the following services: Counseling, psychiatric evaluation, family-centered casework services, psychiatric treatment, vocational planning, school guidance, and coordination of community agency services.

While these social assessment findings may not be applied as a generality to all families who have children with epilepsy, it can be presumed that similar families with similar problems will seek services through an expanded Crippled Children Services program.

About half of the invited private physicians attended and participated in the case conferences in Contra Costa County. Only about 10 per cent of those in San Bernardino County were able to attend, due to the great distances involved in many cases. One or more school representatives attended most of the conferences in both counties when the patient was of school age. Whenever the patient was a client of the welfare or probation departments, an agency worker was usually also present. Counselors from Vocational Rehabilitation Services were present in selected appropriate conferences.

Frequency of seizures at the time of referral varied from one per year to as many as 85 per day (Table 7).

TABLE 6.—Financial Level of Families Referred to the Epilepsy Project

	Contra Costa County (174 Families)	San Bernardino County (54 Families)
	Per Cent	
Receiving public assistance	15	18
Minimum level	12	33
Above minimum level	71	48
Unknown	2	2

TABLE 7.—Frequency of Seizures at Time of Referral to Epilepsy Study Project (Information available for 136 patients)

Seizures	Per Cent
10 or more per day	9
1—10 per day	12
1—6 per week	15
1—4 per month	19
4—11 per year	13
3 or fewer per year	26
Not classifiable	7

One of the criteria of the success of medical therapy of epilepsy is the degree of improvement measured by the reduction in seizure episodes. A majority of patients will become seizure-free, others will show some improvement in that the seizures occur less often and/or are briefer and less severe. A small proportion will not be improved by treatment and may even become worse during the period they are under observation.

Therapy for those who will continue to have seizures must include the education of the patient and his family about partially controlled or uncontrolled epilepsy.¹² Counseling in the form of assurance and guidance is a very essential and necessary part of therapy, for the patients must learn to adjust their lives and occupations to this handicap which can cause only brief periods of total disability. Such efforts will aid in the prevention of serious social and psychological handicapping and they are as important for persons with partially controlled or non-controlled epilepsy as is anti-convulsant drug therapy. Hence an important criterion for the success of a therapeutic program is the degree of social adjustment of the patient and his family to his problem. Because of the short period of observation and study of these patients, this factor could not be determined.

Children who were followed for at least three months after case conference were classified as to frequency of seizures at the time of referral and at the end of the follow-up period (Table 8).

Since these children were admitted to the Project over a period of two years, the length of the follow-up necessarily varied according to the date of referral. Almost 60 per cent of the children were seizure-free at the time they were last seen by their physi-

TABLE 8.—Results of Treatment at Least Three Months After Diagnosis under Epilepsy Study Program (Information available for 136 patients)

	Per Cent
Group I—Seizure-free	58
Group II—50 per cent or more reduction in seizure frequency	24
Group III—Less than 50 per cent reduction in seizure frequency or not improved	18

TABLE 9.—Medical Care Status of Persons Receiving Care Through Epilepsy Project as of December 1, 1962

	Contra Costa County	San Bernardino County
Total number of patients	180	56
Number of active cases	122	38
Receiving treatment from epilepsy specialist, pending stabilization	53	21
Receiving Crippled Children Service from referring physician	48	4
Waiting completion of diagnosis	21	13

TABLE 10.—Medical Care Status of Persons No Longer Receiving Care Through Epilepsy Project as of December 1, 1962

	Contra Costa County	San Bernardino County
Total number of patients	180	56
Inactive cases	58	18
Returned to private care	18	4
Not epilepsy	18	10
Moved out of county	16	3
Died	2	1
Became 21 years of age	2
Withdrew	2

cian, and one-third of these had had no seizures for at least one year.

Over 80 per cent of the children in the two counties showed significant improvement—that is, were either seizure-free or had a reduction of at least 50 per cent in the frequency of seizures after being under treatment for at least three months. These data compare favorably with treatment results recorded in studies in major epilepsy centers and programs elsewhere.^{12,13}

About half of those children having weekly or daily seizures continued to have seizures although most of them showed 50 per cent or more improvement. This fact is an additional indication that the children being referred were representative of problem cases needing comprehensive diagnostic and treatment services.

In certain selected cases of focal epilepsy in which the focus is unilateral and has stabilized, and where medical therapy has not achieved control of seizures, patients may be candidates for neurosurgical removal of the epileptogenic focus.¹¹ One boy in this program did fit these criteria. Hemispherectomy was done and at the time of this report he had been seizure-free for 14 months.

The medical care status of patients receiving care

TABLE 11.—Diagnosis of Patients Found Not to Have Epilepsy, December 1, 1962

	Contra Costa County	San Bernardino County
Number completed diagnosis	160	43
Number diagnosed epilepsy	136	33
Number diagnosed "not epilepsy" ..	24*	10
Severe emotional disturbance	8	2
Nutritional hypoglycemia	2	0
Breath-holding spells	1	4
Febrile seizures	5	0
Other	8	4

*This figure includes six children with breath-holding spells and febrile seizures who were kept under observation of the program.

through the Project on December 1, 1962, is listed in Table 9. About 40 per cent of the case-load were receiving treatment supervision from their private physician and these services were being paid for by the Epilepsy Study Program. The rest were receiving care from the epilepsy specialist under the program or were still undergoing diagnosis.

Table 10 shows that about 13 per cent of children with epilepsy were receiving treatment from their referring physicians on a private basis. These data point out that patients were being returned to their private physicians rather promptly after seizure control had been established or when consultation had been completed.

About 16 per cent of the patients were found not to have epilepsy and data on them are summarized in Table 11. Included in this category are children who had symptoms of seizures during a "breath-holding spell," children with a history of many seizures associated with fever, and two adolescents with episodes of nutritional hypoglycemia. Several children had severe emotional disturbances, and some had seizure-like symptoms on a psychogenic basis. One child had early symptoms of progressive muscular dystrophy; others had questionable seizure-like symptoms in association with a drug reaction, cerebral palsy, hyperactive behavior syndrome, mental retardation and mild emotional problems.

These patients who did not have epilepsy had significant medical histories and symptoms which are similar to the problems that fit into the category of epilepsy. An important function of a diagnostic program is to rule out the suspicion or possibility of a condition, as well as to confirm a correct diagnosis.¹⁵ Therefore, the epilepsy program played an important role in establishing the correct diagnosis, thus leading to the appropriate treatment.

The costs of a complete diagnostic examination as described would amount to \$225 or more per child at current fees. However, because some children had previous diagnostic tests, and others did not complete their diagnostic evaluations in any one fiscal year, the costs of providing these services

approximated \$125 per child per year for diagnosis; and treatment costs were about \$51 per child per year.

SUMMARIZATION OF FINDINGS

The findings of the Epilepsy Study Project substantiated testimony presented to the State Legislature.⁵ Some children with epilepsy and their families do have considerable medical and social problems and are in need of special assistance.

The Project accepted the referral of any child who was suspected of having or had symptoms suggestive of epilepsy in any of its forms. Two hundred and thirty-six children in 228 families were provided services by the Project.

In the two years of the Project, between 10 and 16 per cent of the estimated number of children with epilepsy were provided services in Contra Costa County, and between 2 and 5 per cent in San Bernardino County.

Over half of the children were referred by their physicians because the families could not afford a complete evaluation. The proportion of children referred by physicians was increasing by the time the project terminated.

One in six of the children diagnosed was found not to have epilepsy. Most of these children did have a serious medical and social problem for which they needed help.

Of the children who had epilepsy, almost half had a mixed type of epilepsy, and one in three had focal seizures indicative of previous serious brain injury.

Two-thirds of the children had additional handicapping conditions. These associated conditions were mental retardation, emotional disturbance, cerebral palsy, minimal cerebral dysfunction and other conditions of the brain and sense organs. The services of physician specialists were needed to establish an appropriate diagnosis and to medically control the seizures because of the severity and types of their epilepsy and the associated handicapping conditions.

Most of the children with epilepsy were having uncontrolled seizures at the time of referral, one in five having one or more seizures daily. Three out of five children became free of seizures within the limited observation periods. Another one-fifth had a reduction of 50 per cent or more in the number of their seizures, while the remainder either could not be improved or required further study and treatment to improve their status.

Two-thirds of the families had moderate or severe problems of family functioning. One in five of the families studied were in need of casework or psychiatric services to assist them to cope with problems which disturbed their social functioning. Unless

these families receive such services, these children will very likely not be able to benefit from medical treatment provided.

The major service provided by the Project was to organize a multi-discipline team which could complete an evaluation of the child and his family, and bring together those persons interested in the child to plan and coordinate his care. In so doing the Project was able to determine gaps in community services as well as point out those services needed for the successful treatment of the children.

The Project was able to facilitate the care of the child because it had the funds necessary to pay for the complete evaluation of the child and his family, and to pay for the attendance and participation of the child's physician at the case conference. The case conference was one of the most important and essential features of the diagnostic services, and the interpretative conference with the parents and the child was equally valuable.

An important part of planning for services needed in a broadened program is having information available as to needs, possible problems, and costs. By providing services in limited pilot study areas and simultaneously carrying out program research, this data can be obtained and thus permit better planning and budgeting for services to the larger state population. The Epilepsy Study Project has demonstrated this technique which we believe is a reasonable and practical method of obtaining information necessary to program development, and at the same time has demonstrated the value of needed services.

RECOMMENDATIONS

In view of these findings, the State Department of Public Health recommends:

1. That epilepsy be included in the Crippled Children Services program as an eligible handicapping condition.

2. That Crippled Children Services programs include social work staff to provide social diagnostic services to children with suspected or known epilepsy. A priority should be placed on family-centered social assessment in the diagnostic procedures, collaboration in the development of treatment recommendations, interpretations of findings, and coordination of planning.

3. That social casework and psychiatric services be available to children with epilepsy and their families. The Child Welfare Services of the welfare departments and the Short-Doyle Community Health Services programs seem to be the available and appropriate community resources to support this recommendation.

4. That vocational planning, counseling and training services be made available to the child with epilepsy at the earliest possible age while he is still attending school.

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